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Making the Link: A pilot health navigation intervention to improve timely linkage to care for men who have sex with men and transgender women recently diagnosed with HIV in Guatemala City

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Abstract

Introduction: Men who have sex with men and transgender women across the globe experience barriers to timely linkage-to-HIV care. Health navigation is a strengths-based approach, originally developed for cancer patients, to address these barriers and provide support. We piloted a health navigation strategy to improve timely linkage-to-care among men who have sex with men and transgender women recently diagnosed with HIV in three sexual health clinics in Guatemala City.

Methods: Participants included individuals who were at least 18 years old, identified as a cisgender man or transgender woman, reported having had sex with a man in the past 12 months, and had received a positive HIV diagnosis at one of the participating clinics. Three health navigators were trained in health navigation including: assets-based counselling and support; health system information; and advocacy. We used a combination of quantitative data collected during clinic visits and qualitative data collected through in-depth interviews with participants who accepted navigation to characterize the acceptability, effectiveness, and our primary outcome of time to linkage, defined as having the first clinical care visit.

Results: Out of 61 men who have sex with men and transgender women diagnosed at the participating clinics during the study period, 54 were offered participation and enrolled in our pilot (n=52 men who have sex with men; n=2 transgender women). Fifty participants (92.6%) accepted

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navigation, all who accepted were successfully linked-to-care. The median time to linkage was 3 days (Interquartile Range 2–5 days). In qualitative interviews, participants expressed feeling extremely scared and alone following their diagnosis and appreciated the support of a navigator especially when they did not feel they could access their existing support networks.

Conclusions: Navigation was a highly acceptable and effective strategy for facilitating timely linkage-to-care among newly diagnosed men who have sex with men at participating clinics in Guatemala City. Differentiated approaches should be used to improve engagement with transgender women. Based on these findings, navigation strategies are currently being integrated into HIV prevention and care models in the Central American region. Rigorous implementation science research and evaluation should continue to explore the use of health navigation with key populations recently diagnosed with HIV.

Keywords

HIV; MSM; health navigator; linkage to care; Guatemala

INTRODUCTION

HIV in Central America is largely concentrated among men who have sex with men (MSM) and transgender women (TW). The most recent estimates of HIV prevalence in Guatemala are 10.5% among MSM and 24.0% among TW [1], compared to 0.6% among adults at the national level [2]. Factors including intersectional stigma, related to gender, sexual orientation, and HIV, and lack of social support have been identified as barriers to HIV testing in the Guatemalan context [3,4]. In response to the disproportionate burden of HIV among MSM and TW and the need to improve early HIV diagnosis, in 2006 the U.S. Centres for Disease Control and Prevention (CDC) began supporting the HIV/Sexually Transmitted Infections (STI) Sentinel Surveillance and Control Strategy (known as VICITS, in Spanish). VICITS clinics provide comprehensive STI diagnosis and treatment, voluntary HIV testing and counselling, and behaviour change counselling. There are currently three VICITS clinics in Guatemala City that provide differentiated care for sexual and gender minority populations.

While the VICITS clinics promote population-friendly HIV testing services, the original model did not include strategies for facilitating and systematically collecting data on timely linkage-to-care for individuals who test positive for HIV. Reflecting this lack of linkage strategy, it is estimated that only 35% of people living with HIV in Guatemala are engaged in HIV care, 31% receive ART, and 16% are virally suppressed (viral load <50copies/ml) [5]. Along with the multi-level barriers to HIV testing and accessing healthcare in general, MSM and TW also experience substantial barriers to linking to HIV care in Guatemala [6]. Benefits of timely entry into HIV care include decreased morbidity, mortality and infectiousness, exposure to prevention messages, and support [7–9].

Health systems navigation is a strengths-based model originally developed in the context of cancer care and adapted as a way to address social and structural barriers to HIV care and treatment [10]. Navigators, who are often but not always peers, work with individuals to identify how to use existing resources and secure additional resources, as needed, to

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maintain health and wellbeing, while also serving as advocates and source of social support. Among people living with HIV, having higher social support has been associated with timely linkage to care [11] and the support and close connection to a navigator have been identified as key facilitators of timely linkage [12] and other HIV-related care and treatment outcomes [13].

Since its initial adaptation to HIV, health navigation has increasingly been expanded to facilitate timely linkage to HIV care and accompaniment to initial medical appointments [14–16]. Early research in the U.S. showed that the use of navigators for those recently diagnosed with HIV significantly reduced perceived social and structural barriers to linkage in HIV care (e.g. paying for services, making appointments, finding clinics) [17]. More recently, assistance with medical care and counselling on care and treatment, both activities which can be facilitated by navigators, have been positively associated with linkage to care [18]. Health navigators are increasingly being incorporated into case management teams in low-and middle-income countries to pick up where traditional outreach leaves off and assist people living with HIV to enrol in and access care and treatment services [19].

Navigation is recommended as a strategy specifically for MSM and TW to provide support in negotiating the multi-level, intersecting barriers to timely linkage to HIV care [20,21]. Limited evidence exists, however, of the outcomes of such approaches. A qualitative study in China found that HIV-positive MSM would be more likely to initiate HIV care if they had the assistance of a peer, which included peers in terms of similarity of both HIV status and sexual orientation [22]. In Kenya, Graham et al (2016) tested a tailored intervention to promote linkage-to-care and ART adherence among MSM living with HIV, of which peer navigation was a primary component. Findings from the small pilot test showed that the intervention was well-accepted and feasible for MSM, and a randomized clinical trial (RCT) with this population is currently underway [23]. An RCT with MSM and TW in Myanmar, including peer navigation to support engagement in HIV care and treatment, is also underway [24]. There are no published studies of the results of navigation approaches to promote linkage to HIV care among MSM or TW in Latin America.

To address the gap between HIV diagnosis and linkage-to-care, we piloted a health navigation strategy to improve timely linkage-to care among recently diagnosed MSM and TW in three VICITS clinics in Guatemala City. In this paper, we report key indicators of acceptability, effectiveness, and outcomes (i.e. time to linkage) along with qualitative findings to explain and contextualize our findings.

METHODS

Study setting and intervention:

This study was conducted from November 2014 through March 2015 in Guatemala City, the capital of Guatemala, with a metropolitan population of approximately 4.7 million [25]. The pilot was conducted in 3 VICITS clinics in Guatemala City: Colectivo Amigos Contra el SIDA (CAS) is a non-governmental organization dedicated to the health and rights of gay men; Fundacion Marco Antonio (FMA) is a non-governmental organization with a longstanding STI/HIV clinic for key populations; and one governmental clinic in Zone 3 of

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the city (Z3). All three clinics were easily accessible by public transportation. In order to increase early diagnosis, CAS hosted a free sexual health clinic every Saturday afternoon targeting MSM. Peer educators promoted the Saturday clinics at saunas, gay clubs, public spaces known as gathering spots for gay men and via social media and hook-up sites to encourage gay men and other MSM to come in for holistic sexual health services, including rapid HIV testing and counselling. FMA and Zone 3 clinics offered health care services including HIV testing on a more traditional schedule during business hours Monday to Friday. If a participant tested positive for HIV, they were offered the services of a health navigator to provide support and facilitate timely linkage to care.

Three health navigators, two psychologists and one health educator, were trained in the principles and strategies of health navigation including assets-based counselling and support, health system information, and advocacy. Each navigator supported 10–20 clients during the pilot.

Usually during their first contact, the navigator helped the participant make an appointment for their first HIV-related medical visit and subsequently accompanied them to that appointment. If necessary, navigators accompanied participants to laboratory or other health services appointments as well. In addition, navigators provided information about the HIV care system and emotional support through face-to-face meetings and cell phone contact (i.e. calls, SMS, WhatsApp, social networks), and helped with disclosure to friends, family members or partners, of both the HIV diagnosis and, if needed, sexual orientation. Navigators were instructed to maintain at least weekly contact with their clients through phone, text, and in-person meetings during the duration of the study (November 2014-March 2015).

Study population

The study population included MSM and TW who were at least 18 years old, identified as a cisgender man or transgender woman, reported having had sex with a man in the past 12 months, and had received a positive HIV diagnosis at one of three VICITS clinics. Eligible participants were recruited after their diagnosis. This study was reviewed and approved by the Institutional Review Board of the Universidad del Valle de Guatemala and the University of North Carolina at Chapel Hill, also by the National AIDS Program of Guatemala (MoH).

Study design and methods

We used a combination of qualitative and quantitative methods in this pilot study to describe the acceptability of navigation for linkage-to-care, the initial effectiveness of the approach, and the outcomes in terms of time to linkage. All eligible participants were offered health navigation services within 48 hours of receiving their positive HIV result. Each participant was free to choose their preferred HIV clinic. We obtained socio-demographic and clinical information (i.e., age, date of birth, civil status, date of diagnosis, site of diagnosis, etc.) from the standard VICITS forms of eligible participants who accepted health navigation. Socio-demographic and clinical information (date of diagnosis, date of linkage-to-care, date of subsequent appointments, etc.) collected by health navigators was sent weekly to the project coordinator.

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Acceptability was defined as accepting the support of a navigator among those individuals who enrolled in the pilot study. Effectiveness was measured as the proportion of those who had accepted who were actually linked to care within 3 months of HIV diagnosis. Our linkage to care outcome was defined as the number of days from HIV diagnosis to the first clinical care visit at one of the three HIV care and treatment centres. Time to linkage was calculated in days (calculated in 24 hour increments: <24hrs = 1 day) by subtracting the date of first clinical care visit from the date of HIV diagnosis. All quantitative analyses were performed using R.

We also conducted qualitative in-depth interviews to explore the diagnosis experience and to contextualize the experience of navigation with a sub-sample of 19 MSM who were linked to care with the support of a navigator. At the time of study enrollment, the field team asked participants if they would be willing to be contacted in the future about participating in a qualitative interview. While 22 MSM agreed to be contacted, continual monitoring of thematic saturation (recurring themes related to the study) during data collection was used to determine the final sample size of 19 [26]. The semi-structured interview guide contained questions and probes on the following topics: (1) current living situation and support networks; (2) general perceptions of living with HIV; (3) testing and diagnosis experience; (4) reaction to diagnosis and disclosure; (5) process of linking to care; (6) experience with navigator; and (7) general attitudes about HIV care services received. All interviews were conducted in Spanish by a Guatemalan woman with extensive interview experience, audio-recorded, and transcribed verbatim. We conducted a conventional content analysis using an inductive, data-driven approach [27]. We read transcripts and wrote a memo for each participant to summarize interesting themes. Based on these memos, we developed a codebook that contained both deductive, topical codes that reflected the content of the interview guide (e.g. HIV testing and diagnosis, stigma and discrimination, benefits of navigators, etc.) as well as inductive codes that were based on participant responses (e.g. relationship with navigator, feelings of seclusion, feelings of fear, etc.). The 33 codes were systematically applied to all transcripts using Atlas.ti software version 1.0.50. Outputs from this process were used to develop matrices to further contextualize the quantitative findings and identify illustrative quotes to reflect participant experiences.

RESULTS

Description of the population

Out of a total of 61 MSM and TW diagnosed at the participating clinics during this time period, 7 could not be reached to be part of the study. Fifty-four (87.1%) were offered participation and all of these enrolled in the study. Most of the enrolled participants were MSM (96.3%, n=52) with only 2 TW (3.7%) (Table 1). The median age was 26.5 years (IQR 23.0–34.3). As reflected in Table 1, the majority of participants identified as gay/homosexual (79.5%) or bisexual (18.2%) and were single (95.1%). Nearly one-half (44.9%) had a university degree or some university-level education.

Nearly three-fourths of the diagnoses (72.2%) were made at CAS followed by FMA (22.2%) and VICITS Zone 3 (5.6%).

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Acceptability of navigation

With regard to acceptability, 92.6% (50/54) of enrolled participants accepted navigation. Of the four participants that refused health navigators: he choses to link to care with the support of a friend; one linked to care on their own after initial orientation from a navigator at the time of diagnosis; one was a Central American migrant who returned to his country of origin after diagnosis; and one participant refused navigation without giving an explanation.

In qualitative interviews, the main reasons for accepting navigation was lack of social support and feeling extremely alone and socially isolated at the time of their HIV diagnosis. Most participants felt unable to turn to family and friends for fear of being rejected either because of their diagnosis or what they also perceived to be automatic disclosure of their sexual orientation. Only two of the 19 participants in the qualitative interviews disclosed their diagnosis to family or friends immediately after receiving the news. One 27-year-old participant described why he decided to accept navigation in the following manner:

> Look, when you find out the news [of a positive diagnosis], it impacts your life! It completely changes your way of thinking. In that moment, time, space, nothing exists, only that this is happening to me! I felt so alone in the world, so alone! That was when they told me that they were going to give me some help, that someone was going to accompany me to my first appointment, the confirmation. And believe me, when they told me that…I didn't think about it twice because I said, 'I have no idea what I'm up against!'

Linking to care

Among those who accepted, all (50/50) were linked to HIV care within three months of diagnosis, our indicator of effectiveness. Most (72%) were linked to HIV care at Roosevelt Hospital, 26% to San Juan De Dios Hospital, and only 2.0% to the Guatemalan Institute of Social Security clinic (IGSS) (Table 2).

The median time to linkage was three days (IQR 2–5 days) (Table 2). This far surpassed the original goal of the pilot, which was for all consenting participants to be linked within three months of their diagnosis. Beyond the initial appointment, two-thirds (64.0%) of participants attended three appointments at one of the HIV clinics accompanied by their health navigator during the intervention period, 18.0% four appointments, and almost 10.0% 5 appointments. The number of clinic appointments during the study period varied based on health status of each participant.

Participants reported that health navigators helped to overcome barriers by offering emotional and logistical support, providing concrete steps to link to care, and accompanying them to services. One 23-year-old MSM reported that he likely would not have linked to care without the support of his navigator:

> I think that if this support hadn't arrived maybe I still wouldn't have gone to the clinic, for the same fear, and I think that's a big influence because, it's a fear, a fear of how to start breaking those barriers. And the navigator, I think, is a person that helps you break these little barriers, barriers that prevent you from going to the

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clinic and what comes after, the next step. The truth is it's a very important service to give after having discovered that you're positive.

DISCUSSION

In this mixed-methods study, we found that health navigation was a highly acceptable and effective strategy for linking newly diagnosed MSM and TW to HIV care within days of HIV diagnosis. Preliminary results from a peer navigator study in Cameroon designed to support enrolment and retention of HIV-positive MSM and female sex workers (FSW) had similar findings [28]. During the 9 months prior to a peer navigator intervention in Cameroon, 39% of newly diagnosed MSM and FSW were ever linked to care compared to 82% of newly diagnosed MSM and FSW who were linked to care during the initial 4 months of navigation [28]. While we lacked a comparison group in our study, our findings provide strong support for navigation as a means to promote timely linkage to care. Finally, while the focus of our study was on timely linkage, our findings also suggest that navigation can help to support a positive trajectory of engagement in care as reflected by the number of appointments documented in the months following linkage [29].

Based on the encouraging results of our pilot study, health navigation has been integrated into HIV prevention and care programs in Guatemala and throughout the Central American region. While the navigators in our pilot were psychologists and health educators with extensive HIV counselling experience, as the strategy has been expanded beyond this pilot, a more fluid profile that takes into account both educational level and experience has been used to facilitate sustainability, Navigators team now includes men and women, people with no professional health career but with personal and/or professional experience on HIV services (lawyer, psychologists, HIV counsellor, etc.). Future research is needed to identify key characteristics of navigators to define the profile that can facilitate effectiveness in a sustainable manner. It is also important to consider how navigation can be extended beyond the initial linkage period as many of our participants appreciated sustained engagement with their navigator and would benefit from longer-term accompaniment. Additionally, more assessment is needed to determine the most feasible client load for a navigator, taking into account the variable amounts of support and accompaniment required by clients.

Participants expressed the importance of having the support and accompaniment of a navigator at a moment when they felt fear and loneliness related to their diagnosis. Navigators were able to provide both emotional and instrumental support to avoid delays in linking to HIV care. Among the four participants who did not accept navigation, some had other sources of support, which reflects the importance of navigation being a voluntary service. Others may have benefitted but did not accept navigation in the moment of their diagnosis, which reflects that not everyone is ready for navigation at the time of diagnosis. Even though most participatns in the current study accepted navigation, future navigation efforts should identify strategies to maintain communication with individuals who are recently diagnosed but not ready for immediate navigation or linkage.

We reached fewer TW, though the two TW who did participate both accepted navigation and were linked to care. Our larger representation of MSM most likely reflects that one of the

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participating organizations, CAS, conducted highly effective targeted outreach in the MSM community and offered Saturday clinics. This finding also reflects the need for differentiated care including targeted efforts to engage with and support different key populations [30]. Future navigation efforts will require such targeted outreach in the TW as well as determination of the most acceptable profile for navigators. The acceptability of navigators who were not TW in our study echoes findings from the Dominican Republic, where TW living with HIV explicitly stated their preference for non-TW navigators as they felt that TW navigators would experience the same stigma and discrimination as well as concerns about trust within the TW community [31].

Our study had several limitations. First, we did not have a control group, which limits our ability to attribute our results to the navigation efforts. Our qualitative data, however, indicates that participants did attribute the support of the navigator to their timely linkage. As this was a pilot conducted in the real world setting of three VICITS clinics during a relatively short period, our sample was small and we had very few TW. Future studies of navigation should use more robust designs with larger samples to provide additional evidence of the effectiveness of this strategy. Finally, in our qualitative evaluation we only interviewed participants who accepted navigation. In future research, it will be important to obtain the experiences and perspectives of those who refused health navigation and from health navigators themselves.

CONCLUSION

Health navigation was a highly acceptable and effective strategy for facilitating timely linkage-to-care among newly diagnosed men who have sex with men and transgender women at three VICITS clinics in Guatemala City. Findings also suggest that having the support of a navigator may have helped to initiate positive trajectories of HIV care and treatment, though longitudinal data will be required to confirm this. Future scale-up should focus on creating the most acceptable and sustainable navigation model to continue supporting key populations to enter care in a timely manner following HIV diagnosis.

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Table 1.

Socio-demographic characteristics of participants in health navigation pilot, Guatemala City (N=54)

	MSM (=52) n (%)	TRANS (N=2) n (%)	TOTAL (N=54) n (%)
Age (years) (54/54)			
Median (IQR)	27 (23.0 – 34.7)	23	26.5 (23.0 – 34.3)
Sexual orientation (44/54)			
Gay/Homosexual	33 (78.6)	2 (100.0)	35 (79.5)
Bisexual	8 (19.0)	0 (0)	8 (18.2)
Other	1 (2.4)	0 (0)	1 (2.3)
Highest Education (49/54)			
Completed/Some Middle School	18 (38.3)	1 (50.0)	19 (38.8)
Completed/Some High School	8 (17.0)	0 (0.0)	8 (16.3)
Completed/Some University	21 (44.7)	1 (50.0)	22 (44.9)
Civil status (41/54)			
Single	37 (94.9)	2 (100.0)	39 (95.1)
Married/cohabitating	2 (5.1)	0 (0.0)	2 (4.9)
HIV testing site (54/54)			
CAS	38 (73.1)	1 (50.0)	39 (72.2)
FMA	11 (21.2)	1 (50.0)	12 (22.2)
VICITS Zone 3	3 (5.7)	0 (0.0)	3 (5.6)

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Table 2.

Linkage to care: number of clinic appointments attended and median time to linkage by HIV clinic (N=50) [i]

	Roosevelt (N=36) n (%)	San Juan de Dios (N=13) n (%)	IGSS (N=1) n (%)	TOTAL (N=50)
Number of appointments (visits) attended				
Zero appointments	0 (0)	0 (0)	0 (0)	0 (0)
1 appointment	0 (0)	0 (0)	0 (0)	0 (0)
2 appointment	2 (5.6)	2 (15.4)	0 (0)	4 (8)
3 appointments	23 (63.9)	8 (61.5)	1 (100)	32 (64)
4 appointments	7 (19.4)	2 (15.4)	0 (0)	9 (18)
5 appointments	4 (11.1)	1 (7.7)	0 (0)	5 (10)
Median (IQR)	3 (3 – 4)	3 (3 – 3.5)	-	3 (3 – 4)
Median Time to Linkage (days) (IQR)	4 (3 – 5)	2 (2 – 4.5)	-	3 (2 – 5)

[i] 48 MSM & 2 TW